

Camouflaging

Camouflaging is of course something that all humans do – minor adjustments to fit in and be accepted

Camouflaging for autistic people can be an exhausting and continuous pursuit

Camouflaging can have a devastating impact on an autistic person's health but also the arc of their life

The pressure to camouflage is amplified by poor autism awareness and acceptance

Little Her

The beetle is rubbing his legs together so she cannot hear what the other girls are saying.

The label in her new school dress feels like mummy's special sponge that she uses to scratch away the burnt dinner -the burnt dinner that smells so strongly of spitting fat that it always makes her head ache. The grass of the field feels like it is wrapping itself into her skin and little pink spots are trying to escape. She watches a ladybird and thinks that it looks like a drop of blood. She would like to take the ladybird home and put it in her safe drawer. She will look ladybirds up later when she can finally get home to her bedroom. She misses her bedroom with a physical longing that hurts in her tummy. She wants to get up and spin and spin and spin until the hurting stops but mummy told she had to sit with the other girls now that she is starting school.

The memory of the other girls swoops back into her head like birds from the sky and she tries to look at them all, sitting around her, tied to each other with invisible string.

They are talking words. She knows that it is words coming out of their mouths. The mouths are moving faster and faster. She imagines that she is trying to catch the words like trying to catch butterflies and this makes her laugh and laugh and then she has to spin because the laughing feels so fizzy.

The girls are staring at her with big eyes. The talking stops and they all walk away. From now on, every time she tries to sit with them the eyes stare again and they walk away. She has let mummy down.

The table feels gloopy and sticky under her wrists. The varnish of the wood feels like it is swirling beneath her. She remembers the magical bog in her fairy-tale book and she rubs her arms in fast circles like she is the prince who is trying to escape.

Daddy grabs her hands and knocks the perfect procession of peas placed precisely across her plate. ("P...P...P...P" she hears in her head. "P...P...P...P..." she says to the room). Then the loudness starts and the faces around the swamp table starts to

swell and change and Daddy's breathe smells of shouting. She pinches her skin to stop everything swirling. She won't eat peas again because they sound angry.

She is very excited about school today. Today she is taking her collection of stones in. She has been telling her stones about school for a long time and now they know what to expect. It is very important to know what to expect. She takes extra special care lining them up on her desk ready to show. The words about the stones feel stuffed into her head like they could burst through her ears and her eyes.

The other girls have bought silly things like teddy bears which are for babies.

"The fur on that bear looks like the dead fox in our garden...it smells of medicine" she tells the girl who sits in front because it is true. The girl in front becomes the girl who sits somewhere else.

She lets the teacher touch her stones but she can hear them wriggling in her fingers. She knows they do not like being touched. She starts to tell the other children about her stone friends and the words explode from her head and her whole body is whizzing and popping and she dances with the joy of every detail of every stone.

The children start laughing and laughing and pointing at her and clutching at each other and the stones start crying. The teacher touches her and says some words. She thinks the teacher says she is too much.

"I am too much" she says. The stones become quiet.

Teenage Her

Things are not the same inside her. There is aching in her fingers and when she runs everything feels floppy like her bones have been stolen. Things are not the same on her outside but she doesn't want to look at the new things. Instead she squeezes her eyes shut in the bath and watches the patterns of her pulse like a galaxy of stars on her eyelids. The hair on her legs feels like splinters. She digs at them with her fingertips until ladybirds of blood bubble on her skin.

The other girls mutter together more and more with words that are new and that make them giggle and hug. New words feel heavy. They all sit in the darkened hall together and the boys are sent out but the smell of them remains. The other girls seem to grow bigger with every word. Words are light for them because they already have an invisible dictionary. There is so much that she doesn't understand but she is entirely alone, in this room full of huge girls and their laughing is far too loud. She will just pretend she understands.

When the blood comes, it is not like ladybirds anymore and it really hurts and doesn't stop. It makes her mum's face change so she won't talk about it again. It is always a shock when the blood comes so she is never ready and she has no words to ask. She makes secret parcels of toilet roll and tries not to move. She hides in the toilet cubicle, as quiet as a stone, and listens to the other girls. She practices the patterns of their words in her head. There is a rhythm to their like the rhythm of the dripping cistern. She can remember rhythms.

She lines up her magazines in the order she read the words. She has collected all of the words in her head and she uses them like a secret code. The words let her in to the other girls. She watches the other girls and takes pictures in her head of their eyebrows which are thick with brown pencil. The pencil smells like penny sweets. This makes her think of pennies. She doesn't want to think about this because coins make her wretch and sweat.

She gulps on acid in her throat and drags and scratches the penny sweet pencil across forehead. There is a photo in her head and she copies this hair by hair.

Another girl looks back at her in the mirror. She smells of the newsagents where she gets her magazines.

She thinks and thinks about the other girls. She thinks about every pore on their skin. She thinks she would like to put them under a microscope to learn them. She thinks about the other girls so much that there is no room for anything else. There is no room for food in her head. There is no room for food in her tummy. She never feels hungry. Her bones get sharper and everything feels light.

The other girls say they like her bones. She looks like that girl in the magazine (November issue. Page 24-26. Exclusive. Spotted. New love interest.) Counting calories is like counting stones. Like losing stones. Like likes on Facebook. She counts the likes on Facebook and lines them up.

The boy pushes himself rhythmically against her bones. The weight of him is quieter than the music in the hall; quieter than sharing words with the other girls. Her heartbeat is interesting tonight. In her head she is spinning and spinning alone in and out of the lights of the disco. She can smell his neck chain. The burning in her throat starts.

New words are coming. Like easy. Like slag.

The world spins faster than she can. She cannot keep up. She likes lines not swirls now. So she lines up perfect bloody cuts on her arms. More lines equal less swirls.

Apparently you have to wear a white face and black clothes if you need red on your arms. These are the rules. She likes rules.

So she paints the best white face and the best penny sweet eyebrows (black now: not brown. Black is the rule) and she wears the best black dress. She collects the words and rules about music and places and faces to make and the rules about feelings to say you own. There are no rules about feelings.

People look at the red on her arms with their eyes and ask about her "feelings" with their words. She wonders if they mean the spinning inside her. Her words make their eyes look more and their words word more.

"I feel depressed because I am worried about my exams", she says.

She doesn't and she isn't. She heard it on breakfast television. The presenter never says the world is too loud when it spins.

She gets all A's but the red on her arms still keeps lining up. People's words get louder. The lines start to gather in secret on her thighs.

Young Adult Her

He is all that is in her head. He is all that is in her body. Even her heartbeat has softened. He is all she can think about. She is collecting him. She is lining up all his information. She is becoming a girlfriend. She has read all about being a girlfriend.

He is black and white and rules. He said "I love you. You are mine. You must do this. You must do that." And she does this. And she does that.

He tells the world to stop spinning and it does. She sits in the quiet of his rules.

A spinning starts in her gut. She has noticed a letter is out. Rles. Ules. Ruls. The rules are not the same.

"Why have the rules changed?" she asks.

"They haven't" he says. She watches each letter. The rules are not the same.

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The rule is that she is mad. The rule is that she is making stuff up. The rule is that she is crazy. The rule is that she does not make sense. The rule is she has always been mad. The rule is that she is always making stuff up. The rule is that she has always been crazy. The rule is that she has never made sense. Ask anyone.

She has no one to ask. She has no words to ask. She isn't even entirely sure this is the rule anyway.

The smell of his rules is different. The taste of his rules is different. The different is different and it spins unclaimed around her.

His red marks upon her white body are not lined up. It really bothers her.

He rips his rules straight from her and finds someone who he says makes sense. She spins and roars until it all makes sense. Then she lies down and hurts.

"It makes sense" Dr Word says "You have chronic fatigue". The word why spins on in her head.

Mother Her

She joins her little girl who is spinning patterns in shadows around the quiet of their garden. They spin and weave together and sing noises to the birds and dance their toes through the Velcro grass. They are so alike and there is kindness and truth between them. She is consumed with love for her and she would fight tigers for her right to spin.

The rules of motherhood were hard to line-up. She likes the order of them now.

Her body had groaned with change as she grew her baby. Words from doctors and nurses had blurred under the searchlights in the labour room. The blood pressure cuff smelt of acrid rubber and it made her eyes run. The words said "it was normal to cry with happiness". She couldn't push - she pushed to push but her pushing was wrong. They wheeled her on a trolley of shame onto the operating stage. There was no clapping - only a standard ovation of pain. Pain on top of pain on top of pain. She felt every snip and clip and tear and cut and stab.

The words said that "this was not possible; she was being difficult".

She knew the rules of not being difficult so she did the smile she has learnt and used the best sorry that she had collected. She accepted the blame for all the blood on the floor.

She accepted the blame for the health visitor who tutted out coffee breathe because she didn't talk to the other mums at the baby clinic. She knew she was difficult.

She accepted the blame for the tablets that made her nerves ignite with fire. She knew she was difficult.

She accepted the blame for the counsellor who liked all the lights on and who wore 8 squirts of Chanel on her left wrist and 5 squirts on her right wrist.

She was told she was difficult.

Now she is a difficult mother for her difficult daughter.

"I am going to be difficult", she says.

Menopause Her

Her middle name is tired. Her first name is tired. She likes things to match so she is too tired to call herself anything else but tired. I am Tired Tired Tired.

To be entirely honest with herself, she has been so many people over the years, she has no idea who she is, so she might as full well be Tired Tired Tired.

She is too tired to remember or line things up anymore. She is tired of realising there are no rules. She is tired of being detail's bitch. She is tired of trying to make sense of the insensible.

She is tired of all her senses spinning and being told that she "does not make sense."

Most of all, she is tired of that. "You do not have my senses so, of course, I do not make sense. Oh, just SENSE off", she mutters, incensed. She has collected some marvellous new words for the illogicals in this world.

Everything in her body makes noises now. Everything in her body is out of line and bending too much and hurting too much "oh line yourself up" she mutters at her spinning body parts. She does not appreciate the Brownian chaos of her hormones. Her heartbeat is just showing off, frankly.

She flicks through the familiar photo album in her head.

Each one of her spinning through a different world with different rules and different patterns. Sometimes she barely recognises herself. Sometimes she can barely see herself. She takes her own breath away. She has seen so much. There is too much detail in every moment.

The word "resilient" lines itself up in her head and waits its turn to be claimed.

"I have collected resilience" she thinks.

And her breath spins back in to ease the tiredness of her body.

"Camouflaging is often about a desperate and sometimes subconscious survival battle...camouflaging often develops as a natural adaptation strategy to navigate reality..."

Kajsa Igelstrom, assistant professor of neuroscience at Linköping University in Sweden

Quotes from Autistic Women

"For me, camouflaging and/or masking is getting SO good at living a dual life, consisting of multifaceted selves, that I often feel unsure of where my "centre" is... As I become more comfortable with my autistic quirks, these are no longer binarily silenced (private vs. public etc). However, bottling-up "over the top" reactions for the sake of social-norms, expectations and "the day-to-day equilibrium" comes with its difficulties..."

That is why, when I get home from work, school or socialising, all that de-centred (whether obvious or not) throughout the day ekes out of "the camouflage" And, if it does not have the opportunity to be let out, then tomorrow's mask will have dark circles (more than usual)..."

"Out of work I had nothing left to give, I slept and struggled with everything. At work I was this fully capable person and I bet none of my colleagues believed I'm autistic..."

"...they always ask me what I do on my days off, assuming I am studying or something. No, I am mostly just hiding in a dark room on my own getting over the exhaustion of having to pretend to be like everyone else the rest of the time..."

"...people can assume the person is a is "functioning well"...but don't see the huge effort /spoons it costs to maintain that facade, leaving no energy for anything else..."

“Imagine walking out of your home ~ naked. No shield from the elements. Nothing to protect your raw skin from the world of people, places and things...Some who witness your nudity will cover you up; wrap you in a blanket, try to give you the shirt off their back. Others will ridicule, laugh, say you're seeking attention, an exhibitionist. Others will attack, take advantage, assault you, and blame you for the skin you're in...Clothing is a cloak, a camouflage, a uniform ~ a mask. For me being autistic is having no clothes, and knowing it...”

Biography

Rebecca Simmons is Nursing Lead for the Neurodevelopmental Service, Sussex Partnership NHS Foundation Trust. She is autistic and has ADHD and has adult children who are also autistic with ADHD. Rebecca's work involved listening, thinking and talking about autism and ADHD. Pretty much like her personal life. She has written this in an attempt to blend and represent just some of the shared experiences she hears about every day.

Art by Beth Sutton, Autistic artist who also has ADHD. One of the women who inspire our service.